

Recent advances

Palliative care

J Andrew Billings

Palliative care is defined as comprehensive, interdisciplinary care of patients and families facing a terminal illness, focusing primarily on comfort and support.¹ Key aspects include meticulous symptom control; psychosocial and spiritual care; a personalised management plan that maximises patient-determined quality of life; family oriented care that extends through the time of bereavement; and delivery of coordinated services, especially in the home but also in hospital, extended care facilities, day care centres, and specialised units. In this article I introduce current concepts about palliative care and review advances in this subject over the past five years, highlighting developments of particular interest to generalists.

Methods

My choice of topics derives from my familiarity with patterns of medical practice, particularly in the United States; presentations at meetings; review of current textbooks; and monitoring of general medical journals, selected specialty journals on pain and cancer, and nine palliative care journals (see extra box on the *BMJ*'s website).

Why the need for palliative care?

Numerous recent studies confirm earlier observations that dying people and their families experience a wide range of unmet needs, while receiving very costly care.² One large US study, SUPPORT, underscores many of these problems.³ This investigation enrolled patients who were admitted to an academic hospital with common, severe medical conditions and who had a median survival of six months. Considerable suffering and inappropriate use of resources were observed. Many patients died in pain or with high "symptom burdens."⁴ Doctors proved no better than chance in judging whether their patients wanted cardiopulmonary resuscitation. Family members often experienced social and financial devastation—having to quit a job or suffering major losses of income or savings—because of the illness.

Doctors' prognostic estimates are important to both patients and clinicians in making good decisions about appropriate terminal care. Recent studies indicate not only that doctors seem reluctant to speak to patients about death, but also that they are inaccurate and systematically optimistic about the

Recent advances

Better management of chronic cancer pain through thoughtful use of common analgesics, including opioids, and recognition that neuropathic pain requires additional treatment with anticonvulsants or tricyclic antidepressants

Improved management of other symptoms—gastrointestinal symptoms, dyspnoea, confusional states, and depression

Increasing use of advance care planning to preserve patient autonomy and choice around the time of death, when the capacity to make decisions may be impaired

Improved understanding of the role of artificial feeding and hydration for dying people, especially those with neurological impairments.

General consensus on the acceptability of withholding or withdrawing life sustaining supports and of the rule of double effect, which permits use of opioids and sedatives to relieve suffering even if death may ensue

future, thus delaying timely sharing of information and referral to appropriate palliative care services.⁵

Compared with conventional care, palliative care seems to improve patient and family satisfaction and the identification of their needs while reducing overall costs through decreased use of acute hospital care.⁶ Studies of medical school curriculums, postgraduate physician training programmes,⁷ and standard medical textbooks⁸ reveal disappointingly little attention to end of life issues. However, numerous palliative care journals, textbooks, courses, and websites are now available to help clinicians in providing good terminal care (see extra box on the *BMJ*'s website for details). Increasing evidence confirms that "bedside manner" (communication and psychosocial skills) for terminal care can be taught.⁹

Advances in pain management

Almost all pain faced by terminally ill people can be adequately relieved by simple, easily understood oral

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*A list of journals,
books, and
websites about
palliative care
appears on the
BMJ's website*



Palliative care focuses primarily on alleviation of symptoms and support

regimens that generally do not produce troublesome side effects.¹⁰ However, clinical practice continues to be characterised by unrelieved pain, illogical prescribing of analgesics, and widespread “opiophobia.”

Analgesics for chronic pain should be administered at whatever dose is required to relieve distress. They should be prescribed “around the clock,” based on their duration of action (usually every 4 hours for opioids), not when required, and must be supplemented by a “breakthrough” or “rescue” dose that is given as needed between the regular administrations. The analgesics may be supplemented with adjuvants, such as tricyclic antidepressants, anticonvulsants, psychostimulants, and glucocorticoids. All patients receiving opioids regularly require treatment to prevent constipation. An oral, poorly absorbed opioid antagonist, such as naloxone, can be helpful when usual laxatives are not working.¹¹

Neuropathic pain is increasingly recognised for its importance in pain that is difficult to control.¹² The treatment drugs of choice are anticonvulsants and tricyclic antidepressants. Gabapentin is a first line anticonvulsant drug for neuropathic pain.^{13 14} Tricyclic antidepressants are effective in alleviating neuropathic pain even in patients who are not depressed, while selective serotonin reuptake inhibitors have not shown consistent benefit.¹⁵ Other drugs for managing pain include

- Bisphosphonates to prevent and treat bony metastases and associated pain in a variety of cancers,¹⁶ as well as radioisotopes such as strontium-89
- New opioid preparations, particularly long acting oral formulations and transdermal delivery systems, that simplify drug administration and may have other advantages
- Systemically administered local anaesthetics, such as parenteral lignocaine (lidocaine) or oral mexiletine, and ketamine for neuropathic pain
- Psychostimulants to counteract sedative effect of opioids
- Topical local anaesthetics, such as Emla cream (lignocaine and prilocaine), to reduce skin pain from medical procedures
- Specialised pain relieving procedures, such as nerve blocks and spinal (epidural and intrathecal) analgesia.

Advances in alleviating other symptoms

Gastrointestinal symptoms

The use of prokinetic drugs and new serotonin antagonist antiemetics has improved the management of cancer related gastroparesis, nausea, and vomiting. Octreotide relieves AIDS related diarrhoea and can help in the management of intestinal obstruction. Nutritional supplements, including total parenteral nutrition,¹⁷ have failed to show benefit in patients with advanced cancer who have an intact digestive tract. Progestational drugs, such as megestrol acetate, and glucocorticoids improve anorexia.¹⁸

Dyspnoea

Opioids and oxygen are the drugs of choice for managing dyspnoea, and benzodiazepines are added for the almost inevitably accompanying anxiety. Nebulised opioids have not proved superior to oral or parenteral drugs in managing breathlessness.¹⁹

Confusional states

Delirium in terminally ill people is underrecognised and undertreated, with considerable associated morbidity.²⁰ A study comparing haloperidol, chlorpromazine, and lorazepam in treating delirious AIDS patients confirms that the first two drugs, often in low doses, are superior in managing this condition. Importantly, the neuroleptics improved the organisation of thinking both for patients with agitation or other behavioural disturbances (so called “hyperactive delirium”) and for more tranquil patients with confusion (“hypoactive delirium”), who may not have been routinely treated in the past.²¹

Depression and use of psychostimulants

Depression is common in terminal illness but is under-recognised and undertreated. Many clinicians incorrectly presume that depression is normal or expected in advanced illness, rather than viewing it as a biologically based and treatable form of suffering distinct from sadness.²² The biological signs that usually form the basis of a diagnosis of major depression are often present in a terminal condition but are attributable to the medical illness rather than the psychological state. Clinicians must assess patients for classic depressive signs that cannot be ascribed to the underlying illness (for example, early morning waking that is not due to pain) and rely more on such psychological findings as excessive hopelessness, helplessness, worthlessness, and guilt and suicidal ideation. One study has suggested that simply asking “Are you depressed?” will identify practically all dying people with substantial mood disorders.²³

Because of their rapid onset of action, psychostimulants are now the drugs of choice for treating depression associated with advanced terminal disease.²² Clinicians can prescribe increasing doses of dexamfetamine or methylphenidate over three to four days, watching for a response or toxicity.

Advance care planning

With our expanding ability to prolong life, death increasingly occurs after decisions have been made to forego life sustaining measures. Such decisions are familiar in an intensive care unit, but they may also be

appropriate at home, where hydration or antibiotic treatment may be foregone. Approaches to preserving patient autonomy and choice around the time of death, when the capacity to make informed decisions may be impaired, have been the subject of great interest in the United States. Since so many dying people are no longer able to make decisions, designation of a healthcare proxy is indicated for all adults. Advance care directives are not legally binding in many jurisdictions and are generally not available, retrieved, or honoured during acute hospital care. They also do not influence the use of resources and costs,^{24 25} except perhaps in rare communities or specific institutions that have made systematic efforts to educate the public and make the directives readily available.^{26 27}

Dementia care

Two important observations help to clarify the role of artificial feeding and hydration for dying people, especially those with neurological impairments. Firstly, McCann and colleagues observed symptoms in chronic care patients who stopped drinking. The only evidence of physical suffering was a dry mouth, which was readily treatable with simple mouth care.²⁸ Dehydration in advanced illness therefore does not seem to cause physical discomfort and need not be treated or prevented with artificial hydration. Secondly, patients who are aspiring continue to do so even after placement of nasogastric or percutaneous gastric tubes. Feeding tubes should definitely not be inserted in order to prevent aspiration.²⁹ Among patients aged 65 or over who have gastrostomies placed in hospital, 24% die within 30 days and 63% within a year, suggesting a limited role for this intervention in sustaining life or improving wellbeing.³⁰

Volicer and colleagues have outlined a remarkable “hospice approach” to the care of patients with advanced dementia.³¹ In a special dementia care unit, the staff provide regular conferences to share information with patients’ families and make recommendations about five levels of supportive care—“Full care,” “Do not resuscitate” (DNR), DNR plus “Do not transfer to a hospital” (DNT), DNR plus DNT plus “Do not work up fevers” (DNWU), and all of the above plus “Do not tube feed” (DNTF). In a comparable dementia unit where the only alternate to full care was DNR, a third of patients died receiving full care. In the specialised dementia unit, 62% of patients die with orders for the lowest level of support and only 2% are receiving full care.

Hastening death

No aspect of palliative care has received as much attention recently as the ethics and possible legalisation of physician assisted suicide for terminally ill people. Practical experience in the state of Oregon³² sheds light on the subject. In the first 14 months in which physician assisted suicide was legalised in the state of Oregon, which has a population about 3.5 million and a monthly death rate of about 2400, fewer than two people a month requested and received a prescription for a lethal drug dose, and about half used the prescription.³³ Physicians granted one in six requests



Dr Jack Kevorkian, controversial champion of physician assisted suicide

for a lethal medication, and only one in 10 requests resulted in a suicide.³²

Attention should shift away from the very small number of patients who persistently want to hasten their death to the growing information about the nature of suffering at the end of life, the motivation for seeking hastened death, guidelines on evaluating such requests, and general acceptance by ethicists, clinicians, and the US courts of appropriate management strategies based on widely recognised ethical distinctions.³⁴ No patient should turn to suicide because of treatable, reversible conditions such as pain or other physical suffering, loneliness, depression, anxiety, or concerns about being a burden on the family.³⁵ As many as 60% of dying people who express a wish to hasten their death are depressed and hence have treatable and potentially reversible suffering.²²

Even under the best of care, however, a small fraction of patients, probably less than 1%, will persistently wish to have death hastened.³⁴ These patients seem to be motivated more by concerns about not being able to function at a reasonable physical and mental level or about being a burden, rather than because of physical discomfort. Withholding or withdrawing life sustaining measures according to the wishes of the patient is now commonly endorsed in the United States and some other societies.

Likewise, decisions about foregoing life prolonging measures for incompetent patients can often be made by a proxy, particularly a formally assigned proxy or a close relative. The “rule of double effect”—providing a medical treatment for the purpose of relieving suffering even though a foreseeable, unintended consequence of the treatment is to hasten death—has been broadly accepted, though also criticised.^{36 37} This rule should justify the liberal use of opioids and sedatives to control pain or dyspnoea or even emotional distress in terminal illness, a practice that can assure relief of suffering yet is considered distinct from euthanasia. An additional approach, voluntarily stopping eating and drinking, has been recommended so that patients may hasten their death without requiring a physician’s direct assistance.³⁸ Finally, some commentators have endorsed “terminal” sedation, more accurately termed “sedation for intractable suffering in the dying patient,”³⁹ whereby a terminally ill person with

irremediable suffering is sedated to unconsciousness. If fluids are not provided to such an unconscious patient, death soon ensues. With awareness of these options, physicians are better able to respond to a "bad death" as a medical emergency.⁴⁰

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One hundred years ago Medicine as a Career

My colleagues have committed to my care the function of bidding welcome to old and new students at the beginning of this winter's work. We are glad to see you; we look forward to a closer acquaintance with you, since a good deal of the brightness of our lives is reflected from the cheerfulness and enthusiasm of your youth, and you are necessary to us, for without you the work of the great charity which we serve could not possibly be satisfactorily done.

A short time ago I was in conversation with a gentleman from another country who had been diligently reading a new and unpleasant romance of war from the pen of a great authority on the subject of horse breeding. Dealing with this romance, the gentleman said so many things that seemed to be true, so many things more than seemed to be true, and so many things that

were less than honest, that he made me visibly uncomfortable, and, being polite, he continued:

"And yet your Government appears to manage the teaching hospitals of your metropolis tolerably well." I explained to him that the hospitals were maintained by the bounty of the charitable, and were under no immediate supervision of the Government. "Is it possible?" he said. "But is there no State Department to look after the maintenance of your medical schools?" "None," I said. "But pardon me," he asked, "permit me to inquire, your salaries, by whom are they paid?" "By the students," I said. "but we are not entirely dependent upon school fees—we practise our profession outside." "For you, yes, but does not the State pay science teachers?" "No," I said, "the students pay." "Ah!" he ejaculated, "how rich your students must be." (*BMJ* 1900;ii:993.)